

Testimony to the United States Senate Committee on Finance Re: S2053

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Room SD-215

Dirksen Senate Office Building  
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Filed with:

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Submitted by:

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## SUMMARY

*This testimony is in support of S2053.*

*Implications of the Bill's various constituency groups are addressed as well as a brief review of Community Services for Retarded persons in Rhode Island.*

George W. Gunther, Jr.'s Background:

In the twenty-five years that Mr. Gunther has been in the field of retardation, he has had the opportunity to review services from a variety of perspectives. First, he is the parent of a twenty-five year old woman who is retarded, and resides at the Dr. Joseph H. Ladd Center of which he is the Chief Administrative Officer. He is a past Board Member of the National Association of Retarded Citizens, and a past Board Member of the American Association on Mental Deficiency.

Dr. Robert L. Carl, Jr.'s Background:

During his fifteen year professional career, Dr. Carl has both, directly administered institutional settings in Massachusetts and Ohio, and been responsible for the development of various community services in Rhode Island. He has served as a consultant to the United States Department of Justice, numerous state and private agencies, and to various professional and parent-consumer groups.

In the 1850's, Dr. Samuel Gridley Howe established the first public institution for retarded citizens in this country. Within ten years, Dr. Howe had publicly decried this action, and called for the closure of this facility. He correctly predicted the inhumanity and inappropriateness of institutional care which has faced our retarded children and friends for this past century and a quarter.

Although President John F. Kennedy promoted new national policies in the 1960's to improve our nation's capacity to care for our least fortunate citizenry, 1965 saw the publication of a book\* in graphic pictorial format which documented our inhumanity to institutionalized retarded citizens. When Bengt Nirje, Director of Sweden's organization of parents of retarded children, visited the United States in 1969, he compared the many public institutions housing retarded persons with Nazi Germany's concentration camps.

In 1973, the Federal Government made a major commitment to institutional care for retarded citizens through the Medicaid program. From this date forward, Federal funding has been available to all states for certain institutional and other services. During the past decade, hundreds of millions of Federal dollars have been spent in these state institutions. From 1973 to 1983, we also saw a population reduction in public institutions for retarded citizens by more than 50,000 persons. At this time, fewer than 115,000 persons remain in these public facilities. This population reduction has been the direct result of dozens of Federal law suits, as well as more enlightened state legislation in response to Federal Court decisions.

For years, most professionals in the retardation field have agreed in favor of community care for persons with retardation. Most of us have preached

\*Blatt, Burton, Christmas in Purgatory, Longman, Inc., New York  
New York, 1965

the dual messages of more humane care and lower per person expenditures. Yet many people and most organizations involved in retardation services are apparently terribly threatened by the mere submission of a piece of legislation (S2053) designed to promote community services for retarded citizens, and halt the expenditure of millions of dollars on clearly scandalous institutional care nationwide. In state after state, media exposes Federal and State law suits, advocacy groups complaints all document regularly and publicly the shame of these institutional services. Even the present United States Department of Justice avowedly non-interventionist and non-litigational in posture, has documented the disgrace of public institutional services for retarded citizens in state after state throughout the country.

We wonder what the opponents of S2053 fear? Surely, they cannot favor the past or present conditions? We propose that the following be considered.

The Community Living Amendments Act appears to be a progressive piece of legislation supported by the National Association of Retarded Citizens. If this is so, why is it that Senators and Congressmen have received so much mail against the proposed legislation?

It is the intention of this testimony to avoid a line by line review of the proposed legislation and technical aspects and to address the broader implications as we see it.

Over the last decade in the United States, over some 50,000 persons have left institutions and returned to the community. There now remains about 115,000 persons in institutions for the retarded. This legislation addresses the 115,000 persons in addition to preventing thousands of others from entering institutions in the future.

This legislation encourages the development of a community based residential and day service system to replace the institution. In looking at the United States on a state by state basis, the community based residential and day service system, either does not exist in some states, or exists in a portion of the states, or is an incomplete system in many states where it does exist.

Over the last decade (since the beginning of the ICF-MR program) states have been encouraged to, and indeed have made huge financial investments in institutions, both in improvements to the physical plant and increases in the staff.

The professional groups and persons who are apposed to this legislation, raise some legitimate technical concerns about the element of the legislation, but the primary thrust of the bill is accurate and basically raises a major policy issue for the United States Federal Government, such as, should the Federal Government continue to invest huge sums of money in a system of care - such as large multi-purpose institutions - when all the evidence and professional body of knowledge recognizes this as a system that has outlived its' usefulness to the citizens who are retarded in the United States?

If one were to posit the answer as NO, we should not continue to invest this money in this kind of a system, then one needs to address the elements of a bill that can effect the development of a proper community based system with the corresponding reduction of institutional services in an orderly manner.

The elements need to address these broad concerns:

Retarded Citizens - They need a safe, properly supervised home with sufficient treatment services and a "home" atmosphere, such as a four to six person home for most, but not all. Serving retarded persons is not a geographic issue where one part of a state or country can serve and the

other part cannot. Any service that can be delivered in an institution can be delivered in any neighborhood in America.

Parents and Family - They need assurance that a proper home will exist and be properly supervised and a system of services are in place before you can expect them to embrace an unknown program. Emphasis should be placed on moving as many clients as possible to community settings as fast as possible in an orderly manner, rather than emphasizing the closing of anything. If the openings are successful, the closings will simply follow.

Institution Based Professionals - As previously mentioned, professionals who work in institutions have participated in helping to move over 50,000 persons into the community. The chorus of concerns that is being raised by these groups require assurances that the community system will have the capacity and willingness to serve medically complex persons, medically fragile older persons, and retarded persons who exhibit some behavior problems.

Community Based Professionals - Just as the institution based professionals assisted in placing 50,000 retarded persons in the community, community based professionals participate in providing services to these persons who are now living in the community. Most of the clients, relatively speaking, have been the most capable clients in the institution. With less capable clients now entering the community, they need assurances that staff training and specialized support services will be available to sustain the retarded persons in the community. They also need assurances that the over ninety percent who already live in our neighborhood will not have services reduced as a result of the expanded services for formerly institutionalized persons.



Governor's Offices and Legislatures - Tremendous support from Governors and Legislatures throughout the country has resulted in huge investments of money in the institutions to bring them to the Federally mandated TCF-MR standards which improves the services and insures the continuation of over fifty percent federal reimbursement.

These groups need assurance that some relief would be available to assist the states in the payback of the bonds if these facilities were no longer used. In addition, assistance needs to be provided to states to develop reutilization plans for the institutions which generally have huge real estate value.

Community Acceptance - Assurances need to be provided to the community - at - large to insure all persons that retarded persons will be assimilated in communities to avoid having too many retarded persons living in one location. Proper supervision needs to be assured to alleviate fears of "dumping" persons in their neighborhood.

Unions - To the extent possible, discussions need to be encouraged that could result in re-training the experienced institutional staff to work in the new community based locations.

In conclusion, the basic elements of S2053 are far reaching, long overdue, and correct. To our knowledge, the major organizations involved, support the basic concepts of the Bill, but need assurances, such as, we have previously described in this document.



In support of these contentions, we briefly discussed below some of our experiences in our home state.

In Rhode Island, we have seen a steady, planful decline in the institutional population and a concurrent increase in community services. In 1970, there were 1,260 persons living at the Ladd Center, our single state retardation institution. Today, fewer than 400 persons still live at the Ladd Center. Future developments, now in progress, call for further population reductions to fewer than 200 persons by 1985.

Since 1979, over eighty small community residences for four to six retarded persons have been established in Rhode Island. During this same time, over two hundred new apartment settings have been established. Today, more than eight hundred retarded citizens live in fully or partially assisted community residences. About 2,000 retarded adults attend various developmental or vocational day service programs throughout the state. A statewide Early Intervention Program services over 300 disabled infants and their families. Respite care services, genetic counselling, family subsidy payments to keep retarded persons at home, social services, behavioral training, and specialized health and dental services are all available throughout our state.

Much progress has been made, more remains to be accomplished. Primarily, however, our experience in Rhode Island shows that a combination of responsiveness from the Governor and General Assembly, strong advocacy from parents and friends, reasonable planning, and implementation strategies and a generous and caring public, can provide decent, dignified, and cost-effective services for our retarded citizens. We can settle for nothing less.

S2053 or some reasonable facsimile, will promote these kinds of community based services nationwide.